

Long Term Care
Now and the Next Generation

Final Report

- **Baby Boomers: Who Me?**
- **What Current Consumers Say**
- **What the Experts Say**
- **Survey Data Book**

Introduction

Older adults, those ages 65 and older, are the fastest growing segment of the U.S. population. This dramatic increase is fueled by the famous Baby Boomer Generation (those born between 1946 and 1964) who will begin to turn 65 in 2011. The U.S. Bureau of Census estimates that by 2030 nearly 20% of the population will be older than 65. Obviously, these changes will produce an enormous increase in demand for long term care (LTC) services.

Like the United States, Arizona is not only growing, but is growing older as well. Arizona's population is expected to reach 9 million by 2040 at which time about 20%, or nearly 2 million, will be older than 65. This 169% growth in the older population means a burgeoning reliance on LTC programs. The Arizona Long Term Care System (ALTCS), a part of Arizona's Medicaid, is currently serving approximately 19,000 individuals who are elderly and physically disabled. The LTC system now covers about 4% of the individuals served by Arizona's Medicaid, but consumes approximately 30% of the entire Medicaid budget. The significant cost of LTC services and the expectation of still greater costs as the population grows, subjects this program to a high level of public, private, and legislative scrutiny.

What is the AHCCCS Long Term Care Project?

To determine if both ALTCS in general and long term care in particular are meeting the public's needs, the Arizona Health Care Cost Containment System (AHCCCS) established a Long Term Care Project with two over-arching goals. The first was to understand how the Baby Boomer Generation viewed the current LTC system in Arizona and what services and programs were

necessary to these individuals. The second was to assess current consumer satisfaction with LTC Services by surveying home and community-based and nursing facility consumers.

Engaging Arizonans in their future

To understand if the current system is meeting consumers' needs and to plan accordingly, this project focused on the citizens of Arizona. To meet the first goal, the project involved working with two focus groups of Baby Boomers so that AHCCCS could understand what kind of LTC information this generation requires. Focus group participants were queried to determine what information the near-elderly needed and how it should be delivered.

To meet the second goal, the project surveyed the ALTCS Elderly and Physically Disabled (EPD) population ages 18 and over. In Arizona, the number of citizens 55 or older will increase from 900,000 (1995) to more than 2,100,000 (2020). More than 1,000 consumers currently receiving care in ALTCS responded to the survey and helped determine which services were most important and which providers delivered the best care. The survey also provides a glimpse into how ALTCS services can be improved and whether choice is an issue among today's consumers.

Other Sources of Information

Literature review

The research effort also included a literature review. The intent of this review was to provide a synthesis of information about existing consumer satisfaction surveys that have dealt primarily with the aging population, long term care, and satisfaction with health care. The review also laid the foundation for the design and

development of the AHCCCS Long Term Care Consumer Satisfaction Survey used for this project.

The review showed that the literature on consumer satisfaction with health care services, specifically for those in long term care, is meager. However, the research team was able to locate studies and instruments dealing with consumer satisfaction with health care services in generic. The concept of "consumer satisfaction" has been growing; as such, these generic studies assisted the research team in determining what domains of care might be measured, as well as what "wording" and "scaling" of survey items should be used. More importantly, the research team was able to locate local instruments used by long term care agencies to further identify domains of care for consideration. For those interested in reading and reviewing the entire Literature Review, a copy of Book One, "LTC: What the Experts Say?", can be obtained on AHCCCS' website at www.ahcccs.state.az.us.

The Data Book

AData Book was also prepared to supplement the findings and interpretation of the AHCCCS Long Term Care Consumer Satisfaction Survey. While there are a multitude of ways in which survey data can be presented and formatted, the research team wanted to provide all relevant data but not create "data overload." Therefore, we have included the most relevant of all data tables in Book Two, "What Current Consumers Say," and referred all other data tables to Book Three, "Survey Data Book." Again, any reader wanting to review the entire set of data used to interpret the findings of the survey may obtain a copy of Book Three, "Survey Data Book," by accessing AHCCCS' website at www.ahcccs.state.az.us.

About this Report

This final report has been prepared for policymakers, the profit and nonprofit sectors, elected officials, all those who participated in this process and the people of Arizona. It is the result of work conducted by AHCCCS and Health Services Advisory Group (HSAG), funded by the Flinn Foundation. The Arizona State University Survey Research Lab, a subcontractor on the project, conducted the phone surveys.

This Final Report incorporates material from an earlier *Arizona Community Based Services and Settings Report, October, 2000*, which draws heavily on the executive summaries for the Baby Boomer Focus Groups and the AHCCCS Long Term Care Consumer Satisfaction Survey. This final report includes general discussion of the demographic realities as the Baby Boomer Generation begins to retire and rely upon the services and programs of ALTCS. After careful discussion, the research team documented a variety of policy findings associated with the comments and issues raised by focus group participants. Readers interested in reviewing each of the policy findings are encouraged to read Book Four, "Baby Boomers: Who Me?". Or those readers interested in reviewing the complete results of the survey are encouraged to request Book Two. Again, these Books can be obtained on AHCCCS' website at www.ahcccs.state.az.us.



Q) Who Needs Long Term Care Information and Education?

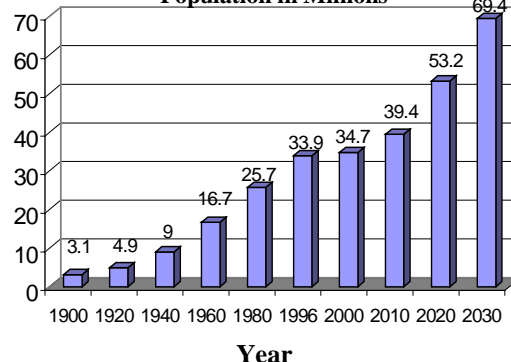
A) Baby Boomers

Older adults, those ages 65 and older, are the fastest growing segment of the U.S. population. This dramatic increase is fueled by the famous Baby Boomer Generation (those born between 1946 and 1964) who will begin to turn 65 in 2011. The U.S. Bureau of Census estimates that by 2030 nearly 20% of the population will be older than 65. Obviously, these changes will produce an enormous increase in demand for LTC services. Is the country prepared for this? Is Arizona?

Like the United States, Arizona is not only growing, but is growing older as well. Arizona's population is expected to reach 9 million by 2040 at which time about 20%, or nearly 2 million, will be older than 65. This 169% growth in the older population means a burgeoning reliance on LTC programs. The Arizona Long Term Care System (ALTCS, a part of Arizona's Medicaid), currently serving approximately 19,000 individuals who are elderly and physically disabled. The LTC system now covers about 4% of the individuals served by Arizona's Medicaid, but consumes approximately 30% of the entire Medicaid budget. The significant cost of LTC services and the expectation of still greater costs as the population grows, subjects this program to a high level of public, private, and legislative scrutiny.

FIGURE 1

**Persons 65+ in the US : 1900 to 2030
Population in Millions**

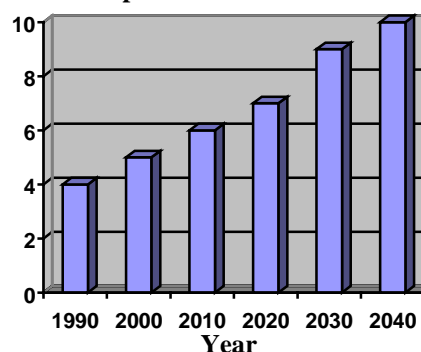


Based on current trends, by the year 2020 up to 14 million elderly will need long term care – double the seven million who need long term care today.

Chronic Care in America, Robert Wood Johnson Foundation. 1996.

FIGURE 2

**Persons in Arizona: 1990 to 2040
Population in Millions**



Are Arizona's Baby Boomers Planning for LTC Needs?

A*bsolutely not*, according to the focus groups. There is a growing body of research indicating that Baby Boomers are consumed by day-to-day activities and expenses and as such, have given little thought to planning for the possibility of long term care. According to a 1997 study conducted in Minnesota, Baby Boomers have convinced themselves that they probably will never go to a nursing home or need other long term care services.

Participants in the Baby Boomer focus groups expressed belief in this same sense of invincibility. They had little knowledge of how the LTC system worked in Arizona, and they did not know who provided it or paid for these services. However, they quickly realized that they would be wise to reconsider the need to have this information and knowledge.

Because of Arizona's rapidly aging population, there is a great need to plan for the future of Arizona's LTC system. In this study, AHCCCS set out to understand what kind of LTC information and services the Baby Boomer generation requires.

Invincibility?

"...It is much easier for me to think about (LTC) for people the age of my parents"

"Yeah, this does not happen to us"

"Just thought it would never be for me"

Baby Boomer Focus Group Members

Among people who have chronic conditions, at least one in three does not understand what services they are eligible for, how to use them, or who provides them. A combination of financial issues, eligibility requirements and specific factors of individual conditions cause a significant number of chronically ill people to feel frustrated with the system designed to help them.

Chronic Care in America, Robert Wood Johnson Foundation, 1996.



Is LTC Information both Available and Clear?

Not according to the focus group participants, who were very vocal about their frustration in trying to find information for either their family or friends. Both groups resoundingly told us that LTC information is:

- Difficult to find,
- Not available or not helpful,
- Usually sought when there was a crisis such as having a family member in the hospital and needing more care at the time of discharge than the family could provide, and
- Difficult to navigate because it is not clear.

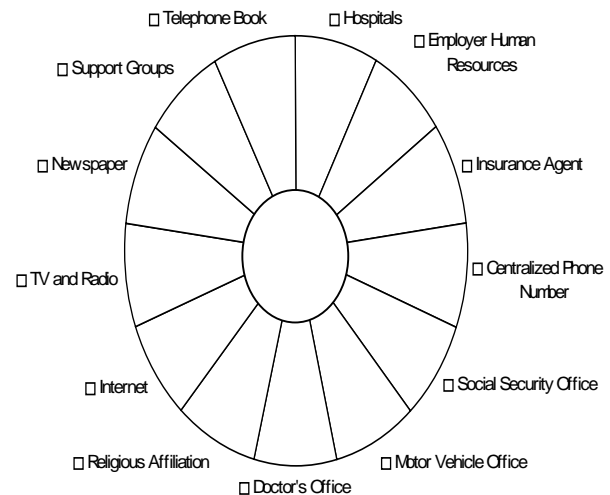
Where to find information?

Focus group participants believed that a central "clearinghouse" would improve the accessibility of information. Such a system could direct individuals to the right agency at the most appropriate time.

Many of the focus group participants believed the primary sources of help and information were hospital social workers, employers, the Social Security Administration, and nonprofit organizations.

In addition, the participants stressed that written information should be available at the various sites (e.g., brochures on whom to contact for more information or lengthier documents on who can become eligible).

The following chart depicts the sources the focus group participants recommended for LTC information.



Among the many places a consumer can access LTC information is the Internet. Both focus groups repeatedly identified the Internet as a viable method for communicating with consumers, especially those with disabilities. This is further supported by a recent Harris Poll as shown in the dialog box below.

52 percent of disabled adults report the Internet has better informed them about the world versus 39 percent of adults without disabilities.

Health Care Purchaser, July 2000

What Should be the Role of the Government?

There were many opinions on the role of the private sector (business and industry), the public sector (government and community organizations), and individuals in paying for health care services. This was especially true for LTC services.

According to the participants, the government's role in LTC should be to:

- Coordinate and access information and services,
- Provide financial assistance, and
- Regulate/monitor quality of services.

Many people do not know how to plan for their LTC needs and are confused by the many messages they hear and read. Frequently, it is not until a person needs LTC services that the individual begins to understand how these services are financed and what role the individual may need to play. As such, many individuals end up relying on Medicaid (ALTCS) after exhausting most of their life savings.

Focus group comments, listed below, give the LTC system insight on how the government can help Baby Boomers plan and access long term care services and information.

- Decisions are currently being made in a crisis mode rather than in a proactive, planning mode.
- The system needs to help both full-pay individuals and those needing financial assistance to navigate the complexities of the bureaucracy.
- The state needs to develop a comprehensive approach to deal with the growing demand for LTC services.

- The government should offer case management before persons enter government programs.
- Financial eligibility needs to be changed, particularly how the government looks at assets. Consumers should not be faced with poverty or destitution before the system responds.
- Baby Boomers want more involvement in how their needs are met.
- Cultural aspects need to be considered because these aspects will affect the way individuals provide care to their family members.

Who Should be the Messenger?

Focus group participants indicated that the government, along with employers, the health care industry, social service organizations and non-profit groups, should be the messenger(s) for LTC. Currently the government is responsible for regulating and monitoring LTC providers and, as such, is in an excellent position to deliver information to consumers. Participants also suggested a LTC Coalition to be a LTC messenger. This coalition might include employers, the health care industry, social service organizations and other non-profit groups to allow for a more widely disseminated LTC message, which needs the support of many businesses and organizations.



What Should the LTC Message Be?

For government to grab the attention of Baby Boomers, the LTC message should focus on the realities aging Baby Boomers face now and in the future. The message should *provide information* rather than attempt to sell a product or service. The government can be of greatest help with LTC information that enables Boomers to take proactive steps and make informed decisions about possible LTC needs.

How Should the Message be Presented?

Years ago, Marshall McLuan spoke of the "Medium in the Message." How information is presented affects both how it is valued and how it is used to make decisions. Both the presentation format and content are crucial to help consumers make informed choices.

What kind of message do consumers relate to?

The Baby Boomers in the focus groups said the LTC message should be:

- Simple and easy to understand (in a lay person's terms)
- Positive
- Clear and understandable
- Offered in several languages

"I hope there are happy faces. Something that makes us feel good about thinking about this (LTC). I mean, nobody wants to think about somebody sitting in a chair with a diaper over them or whatever."

Baby Boomer Focus Group

- Offered in advance of when they will need the service (either for themselves or their families)
- Sensitive to cultural needs
- Presented in a colorful and graphic format they can relate to (not medical or depressing)
- Detailed in some areas and brief in others, with instructions on where to find additional information (such as Internet sites and location maps).

What do Arizona Baby Boomers Say about LTC?

Focus group participants were asked about the shortcomings of the current LTC system. They were asked to describe their concerns and identify what supports they need now as caregivers and what they will need in the future as consumers. The focus groups were clear on four major areas the system needs to work on: 1) information; 2) caregiving; 3) quality; and 4) services.

An ideal LTC system would provide:

Information

- Make known whom to contact to access services
- Distribute information on choices
- Provide a centralized place to receive help in understanding choices and coordinating services
- Educate consumers on issues that impact choices and decisions
- Develop prevention messages

Caregiving

- Support the role of family and community in providing care
- Promote caregiving by family and friends rather than strangers
- Pay family caregivers
- Train and support caregivers

Quality

- Share with consumers information/data on care ratios of nurses/aides.
- Treat consumers with respect and dignity

- Make known whom to contact to make a complaint
- Educate consumers and about which providers are providing quality services
- Increase oversight for quality concerns
- Provide more personal service (instead of automated phone banks, etc.)

Services

- Provide prevention programs
- Provide choice of care instead of directing the kind of care that is convenient to the system
- Consistently provide services promised
- Offer more respite services
- Improve agency coordination
- Reduce waiting lists for services
- Reduce isolation
- Provide qualified and competent workers
- Maintain identity with language and culture after consumer enters the LTC system
- Explain/provide financial assistance

Does the System Need to Change to be More Aligned with Consumer Preferences?

Yes. Arizona is currently developing policies and principles that will guide changes in Arizona's LTC system. One of the state's major goals is to continue fostering the development of a statewide, comprehensive LTC system that maximizes independence and quality of life while recognizing the need for interdependence and support.

More people are living longer, a great deal longer than society has ever had to provide for in the past. Our nation needs a program that rallies existing resources and recruits new talents to meet the demographic realities facing us.

Chronic Care in America, Robert Wood Johnson Foundation, 1996

Order person with disabilities (see Figure 3). Almost 75% of the elderly with

disabilities receive home care through relatives, friends and neighbors. ***Informal caregiving is still the backbone of LTC.*** The role of family and the community in providing informal care will continue to be a critical component of addressing LTC needs of the elderly and disabled because of the shortage of health care professionals. The Baby Boomers will begin retiring in 2011, a trickle that over the next 20 years will become a torrent of individuals who may need care. This will further complicate the LTC labor shortage issue. The state will need to continue addressing this national and state need.

Figure 3

The Shrinking Pool of Potential Caregivers



Focus group participants categorized what was most important to them as follows:

- Provide a centralized place to find LTC information;

"If you don't know the language, if you don't know who to go to from the get go, there is very little help that any one agency will give you in order to tag you into another agency. So it is not a central operation at all."

Baby Boomer Focus Group

- Develop a LTC message that can educate about planning and accessing services with businesses, the health industry, social service and non-profit organizations;

"Today is the tomorrow you were worried about yesterday. Today is the tomorrow you didn't worry about yesterday."

Baby Boomer Focus Group

- Provide LTC information to increase the likelihood that consumers needing services will receive culturally sensitive information before they are in a crisis;

"...I would hope that this organization ...focus(es) on our ideas ...culturally and language sensitive too to embrace all peoples, as well as the blind and deaf, besides Hispanics, Asian, you name it."

Baby Boomer Focus Group

- For individuals seeking to remain at home, provide more choices for in-home services including a better transportation system;
- Address quality of life within the LTC system;
- Ensure qualified caregivers that are:
 - ✓ Competent,

"I am not going to have to go somewhere where I am completely dependent... I can still maintain some self reliance or some independence and be of help to others and I really think this is the generation that is going to know about doing that."

Baby Boomer Focus Group

- ✓ Enjoying what they do,
- ✓ Flexible,
- ✓ Hard working,
- ✓ Providers of good customer service,
- ✓ Paid well,
- ✓ Good with people skills,
- ✓ Sensitive to individual needs,
- ✓ Reliable,
- ✓ Trustworthy, and
- ✓ Helpful to caregivers who are family and friends;

"Being Latina... I don't know if being true American or whatever that you'll agree with me or what, but most people of color don't really use a lot of nursing homes. We bring them home with us and now days we can't. I work and my husband works..."

Baby Boomer Focus Group

- Fund additional tax incentives for LTC; and
- Create policies that do not cause consumers and families to become destitute and impoverished before they are eligible for services.

"We are all Baby Boomers going to need the care."..."You shouldn't have to be in poverty or destitute before you can get any type of help. I mean it is ludicrous. You have to be out on the streets before you can get any type of aide."

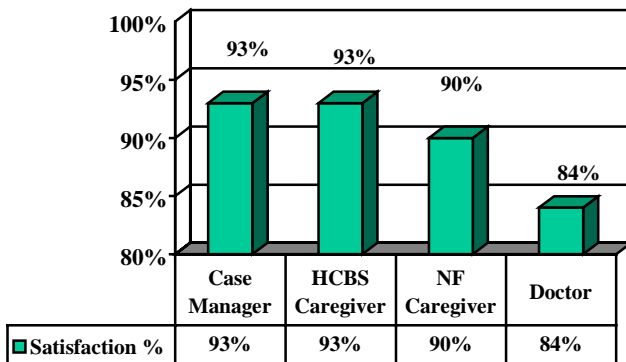
Baby Boomer Focus Group

Q) Is Arizona Taking Care of Long Term Care Business?

A) Yes

CONSUMERS SPEAK OUT

**Figure 4: Consumers Overall
are Either Very Satisfied or Satisfied
with LTC Providers**



What is the Report About?

The Long Term Care Consumer Satisfaction Survey was conducted with 1,031 individuals receiving Medicaid long term care services either in home and community-based settings or nursing facilities. The survey measured the elderly and physically disabled members' satisfaction before a consumer had health plan choices. The survey's goals were to: 1) determine what long term care services are important to consumers; 2) assess current satisfaction with the long term care system; and 3) compare satisfaction levels between existing consumers.

For the first time, Arizona is offering ALTCS consumers choice of three managed care plans in Maricopa County. As of October 2000, Maricopa long term care consumers have a choice of three long term, managed-care organizations (59% of LTC members reside in this county). Following this change, the Medicaid agency, the Arizona Health Care Cost Containment System (AHCCCS), wanted to take the opportunity to ask current consumers if AHCCCS was taking care of long term care business.

Overall, this survey showed that consumers are very satisfied to satisfied with their providers-case manager, doctor, caregiver in HCBS and caregiver in a nursing facility.

HOW ARE WE DOING?

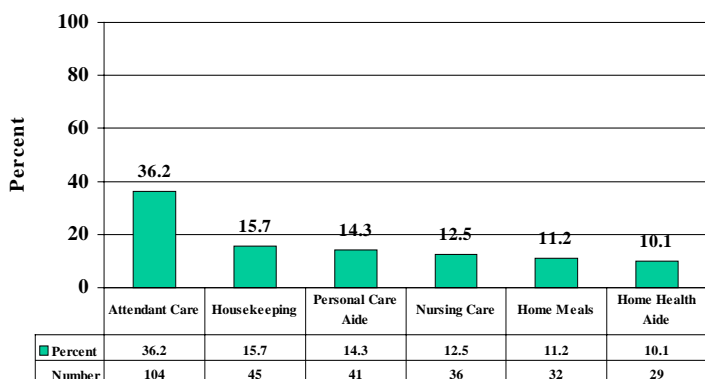


What Services are Most Important to Consumers?

The ALTCS consumers were asked to speak about the most important service they received and their level of satisfaction with the caregiver.

HCBS consumers identified attendant care as the most important service, followed by housekeeping, personal care, nursing care, home meals and home health aide (see Figure 5).

Figure 5: Most Important Services for HCBS Consumers
Total Respondents = 287



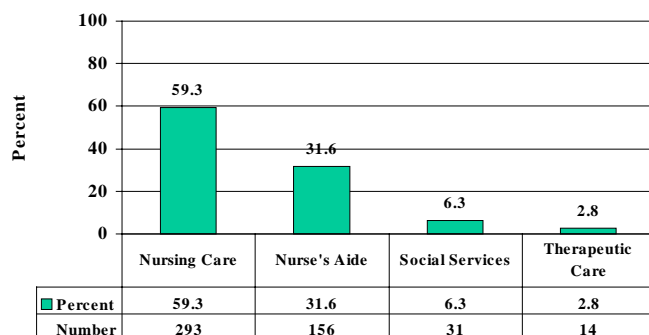
Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents.

"Everything I've ever wanted in terms of home care services is provided to me, I'm very lucky and thankful."

Satisfaction Survey Consumer

Nursing facility consumers identified nursing care as the most important service, followed by nurse's aides, social services and therapeutic care (see Figure 6).

Figure 6: Most Important Services for Consumers in Nursing Facilities
Total Respondents = 494



Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents.

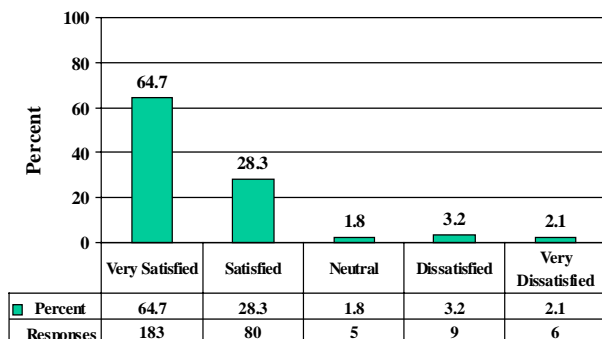


CAREGIVERS IN HCBS

Consumers and proxies were 93% very satisfied/satisfied with their HCBS caregiver

The evaluation of HCBS care by consumer or proxy was based on the service the consumer was receiving and believed to be most important (see Figure 5). The graph below shows the overall satisfaction levels consumers had for their most important caregiver. The consumer was asked to rate the provider in five areas: shows respect, provides help, listens to consumer, involves consumer, and is reachable.

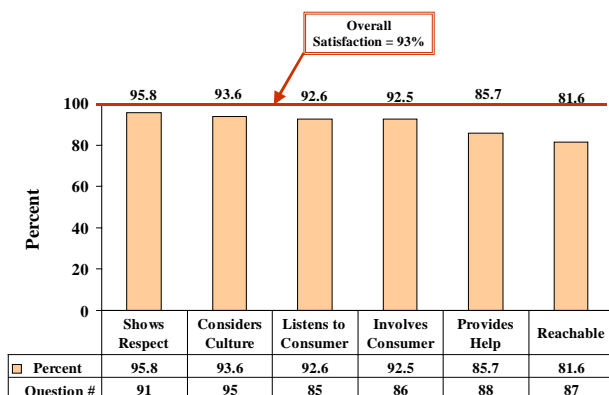
Figure 7: Overall Satisfaction with HCBS Care giver
Total Responses = 283



Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents.

Consumers showed that they are very satisfied to satisfied with their most important caregiver. The percentages range from 95.8% (shows respect) to 81.6% (is reachable).

Figure 8: Consumers Who are Very Satisfied or Satisfied with HCBS Care giver

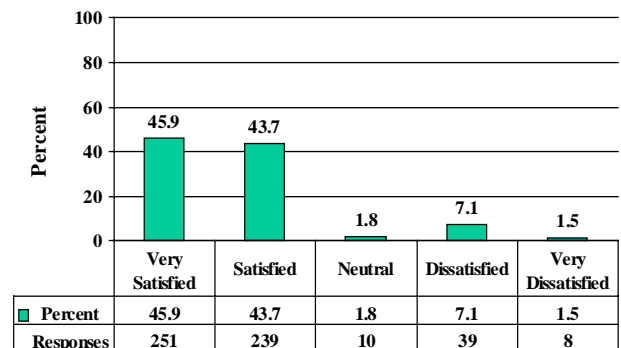


CAREGIVERS IN NF

Consumers and proxies were 90% very satisfied/satisfied with their NF caregiver

The consumer's evaluation of the nursing facility caregiver was based on the NF service the consumer was receiving and believed to be most important (see Figure 6). The graph below shows the overall satisfaction levels for consumers with their NF caregiver.

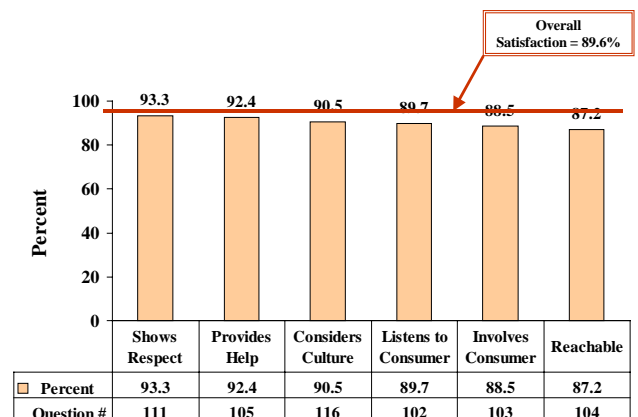
Figure 9: Overall Satisfaction with NF Care giver
Total Responses = 547



Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents.

The consumers showed they were very satisfied to satisfied with their nursing facility caregiver. The percentages ranged from 93.3% (shows respect) to 87.2% (is reachable).

Figure 10: Consumers Who are Very Satisfied or Satisfied with NF Care giver

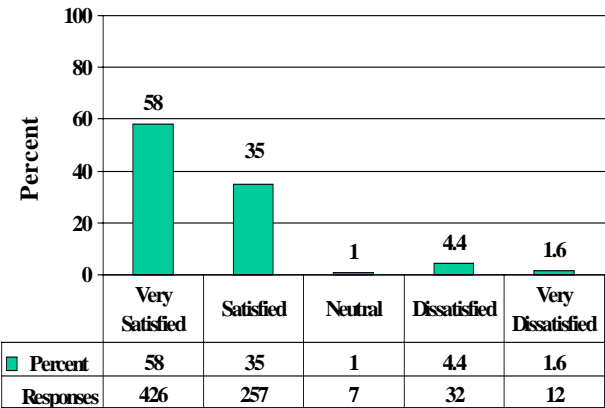


CASE MANAGER

Consumers and proxies were 93% very satisfied/satisfied with their case manager

The survey shows that the majority of the consumers were very satisfied or satisfied with their case manager (see Figure 11).

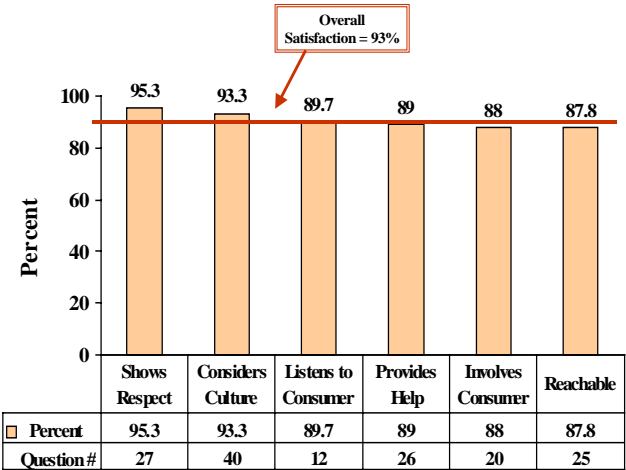
Figure 11: Overall Satisfaction with Case Manager
Total Responses = 734



Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents.

Consumers rated case managers in five key areas (see Figure 12) with results ranging from a high satisfaction rate of 95% for case managers who show respect to 87.8% for case managers who are reachable.

Figure 12: Consumers Who are Satisfied or Very Satisfied with Case Managers



"All the case managers I've had experience with have been excellent."
Satisfaction Survey Consumer

In addition, 74% of respondents knew their case manager. Respondents in the nursing facility were less likely (61%) to know their case manager than those in the home (88%). With 26% of the respondents not knowing their case managers, the question is, "Why"? Were these responses a result of the consumer:

- Not recognizing the term "case manager;"
- Not knowing them; or
- Another reason?

This issue will be further explored in a later study.

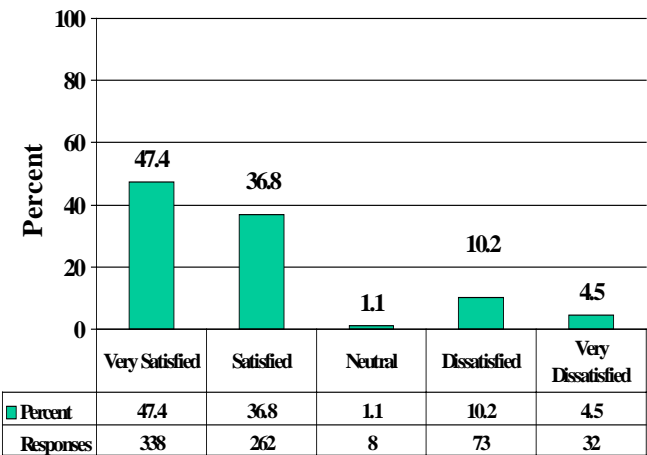


DOCTOR

Consumers and proxies were 84% very satisfied/satisfied with their AHCCCS doctor

All respondents were asked if they knew their doctor. Seventy-four percent did. NF respondents were less likely to know their doctor (62%) than those living at home (86%). In addition, the consumer respondents (86%) were more likely to know their doctor than proxies (70%).

Figure 13: Overall Satisfaction with AHCCCS Doctor
Total Respondents = 713

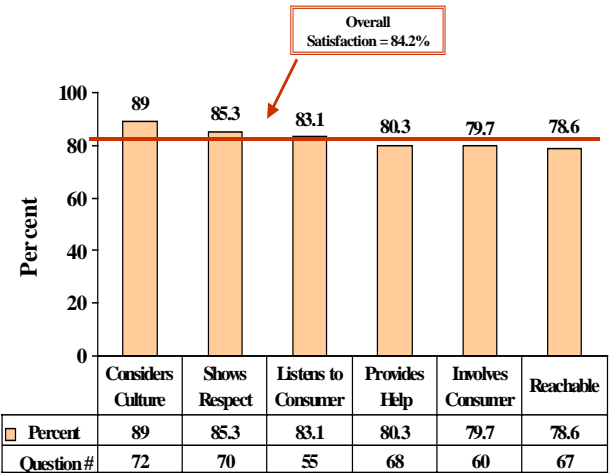


Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents.



Consumers rated their doctors in five key areas. The results indicate the highest rating showing respect (85.3%) and the lowest rating was the doctor being available for consumers.

Figure 14: Consumers Who are Very Satisfied or Satisfied with AHCCCS Doctors



What Other Aspects Affect Consumer Satisfaction?

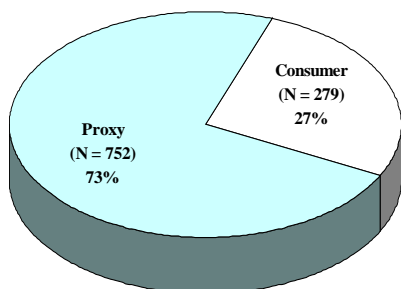
To determine if there are differences in the way consumers responded to the survey, analyses were conducted based on the following groupings:

- Proxy vs. consumer,
- Placement (HCBS or NF), or
- Ages (18-64 or 65+).

PROXY VS. CONSUMER

As previously indicated, there was a total of 1,031 respondents to the survey. A total of 752 (73%) were proxy respondents and 279 (27%) were consumer respondents (see Figure 15).

Figure 15: Is Respondent the Consumer or a Proxy?
Total Respondents = 1,031



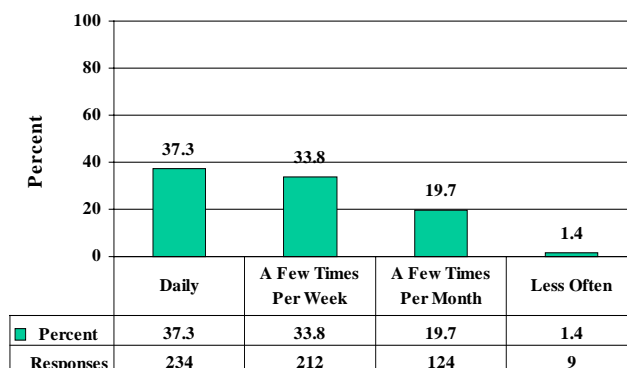
To determine if the proxy-versus-consumer grouping affected the level of satisfaction, researchers analyzed whether an individual was a proxy or a consumer. The following statistical differences were found. Areas that showed statistically significant differences were:

- Consumers were more likely to know their doctor (86%) than proxies (70%).
- Consumers were overall more satisfied with doctors (88%) than the proxies (84%).
- Consumers were more satisfied (92%) with a doctor showing respect than were proxies (83%).

- Consumers were more satisfied (87%) with their doctor involving them than did proxies (81%).

There was a high degree of proxy involvement (see Figure 16). More than 70% of proxy respondents were involved with their consumer either daily or a few times per week.

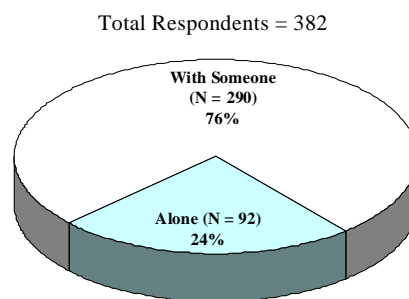
Figure 16: Degree of Proxy Involvement
Total Respondents = 579



Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents. There were 752 proxy respondents for the survey.

In addition, the survey shows that most consumers live with someone or have family nearby.

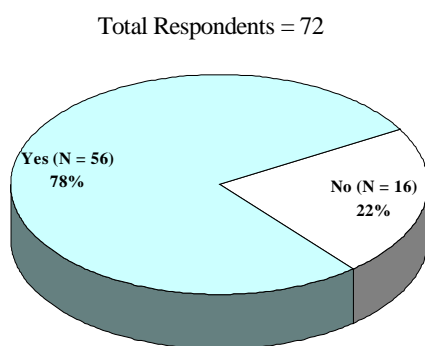
Figure 17: Consumer Lives Alone or With Someone



Note: Not all questions were answered by all respondents.

The results indicate that proxies can provide meaningful information to Arizona's long term care system. In addition, this survey clearly shows that proxies are important caregivers in many situations as well as consumers of long term care services for their family or friends.

Figure 18: Consumer Has Family and/or Friends Near



Note: Not all questions were answered by all respondents.

BY PLACEMENT

To determine if the consumer's place of residence (referred to as placement) affected the level of satisfaction, an analysis was conducted between those consumers who lived in home and community-based settings and those who lived in a nursing facility. The following statistical differences were found in the home and community-based setting versus the nursing facility setting.

HCBS consumers compared to NF consumers were more satisfied with:

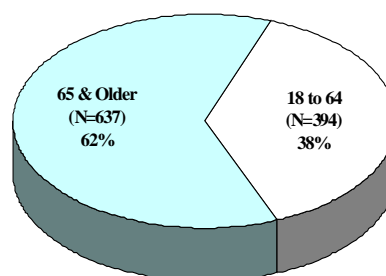
- Knowing their case manager (88%) to (61%).
- Case manager listening skills (94%) to (91%).

- Case manager providing help (91%) to (84%).
- Case manager involving them in decision-making (94%) to (91%).
- Overall satisfaction of their doctor (90%) to (79%).
- Doctors providing help (85%) to (74%).
- Doctor's listening skills (90%) to (79%).
- Doctors involving them in decision-making (91%) to (72%).
- Doctor being very easy to easy to reach (68%) to (61%).
- Doctor respecting them (94%) to (81%).

BY AGE

To determine if age affected the level of satisfaction, an analysis was conducted between two age groups.

Figure 19: Distribution of Age Among All 1,031 Respondents

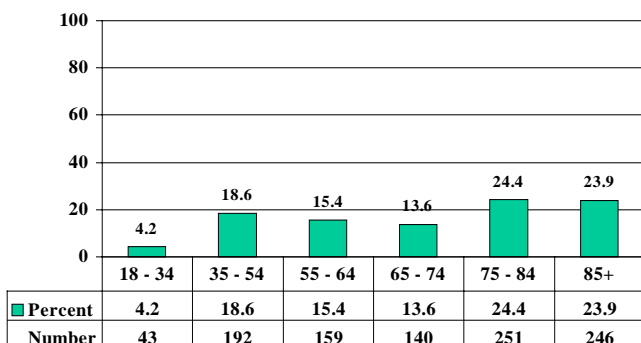


Notes: Mean Age = 69.6 Years

The following statistical differences were found between those consumers in the 18-64 age group vs. those consumers in the 65+ age group. Consumers who were 18-64 years of age were overall less satisfied with the case managers.

- Overall (91%) to (96%).
- Involving them in decision-making (90%) to (95%).
- Reachability (88%) to (93%).
- Showing respect (93%) to (98%).

Figure 20: Distribution of Age Groups
Among All 1,031 Respondents



Do Consumers Want Health Plan Choices?

A? B? C?

Several weeks before this survey began, ALTCS consumers in Maricopa County received information regarding a first-time opportunity to choose among health plans for their long term care services.

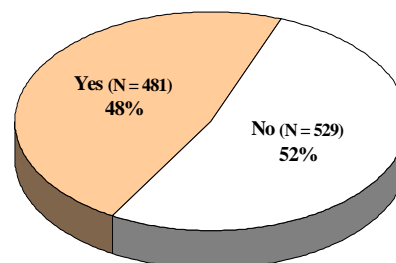
Forty-six percent of the consumers participating in the pre-choice satisfaction survey were interested in receiving more health plan choice. A post-choice survey in the fall of 2001 will look at why or why not consumers or proxies changed health plans. The survey will also assess if satisfaction levels changed.

Do Consumers Know How to Register a Complaint?

Measuring consumers' knowledge about how and where to file a complaint was an important step in assessing satisfaction with long term care providers and services. Forty-eight percent of respondents indicated they know how to contact Maricopa Long Term Care about complaints (see Figure 21).

Of those who filed a complaint, 99.2%, indicated they were very satisfied to satisfied that the complaint was handled fairly.

Figure 21: Consumer Knows How to Contact Maricopa County Long Term Care About Complaints After Seeking Help from Case Manager
Total Respondents = 1,010



Notes: Percents may not add to 100 due to rounding.
Not all questions were answered by all respondents.

What are the Policy Issues?

CONCLUSION

The results of the focus groups and the Long Term Care Consumer Satisfaction Survey were compiled into seven policy issues to guide state leaders as they reform the long term care system in general and improve ALTCS in particular. In late 2001, the research team will re-interview the initial respondents by telephone with the same survey tool. Data will be compared to the current consumer survey, which will function as the base line tool. At that time, a comparison report of the new findings will be shared with the community.

What Should be Done to Help Baby Boomers Plan for Long Term Care?

A lot. Participants of both focus groups said they had put little thought into long term care for their parents, let alone themselves. They did not understand who would pay for the service when they needed it. Those with some long term care experience said that all too often they had waited until a family member was in a crisis before seeking help.

Policy Issue:

- Develop an awareness campaign to educate Baby Boomers about the need to plan, much as they already do financially for their retirement.
- Develop a better understanding of long term care financing, the makeup of the population currently receiving services and the impact on our communities.
- Hold wide-ranging discussions about the role of government in providing long term care services.

Who Needs Better Long Term Care Education and Information?

Seniors, Baby Boomers, Generation Xers - everyone. Research participants either had no real sense about where to go for information, or their understanding of long term care was shallow. The few who had looked for information said they were frustrated because they couldn't find it, or what they did find was not easy to understand.

Policy Issue:

- Educate, educate. Specifically, pilot a long term care education outreach program through human resource departments in a variety of businesses.
- Form partnerships to ease the flow of long term care information by creating a web site among health-related state agencies to centralize information; centralizing information at a physical location with staffing to help the public; and establishing a collaborative effort among state agencies and private organizations to distribute written material.
- Provide information that is culturally sensitive.

Who Actually can we Call the "ALTCS" Customer?

After surveying 1,031 ALTCS consumers, one result was surprising: 752 of them, or 73 percent, were proxy respondents, while only 279, or 27 percent, were actual "customers" enrolled in the program. What does this show? That proxies, or caregivers, are a

valuable source of information because they are so involved with the actual user. This finding has implications for the non-ALTCS population as well.

Policy Issue:

- State policymakers, when considering the future of ALTCS, must re-think their definition of "customer" by (1) recognizing that proxies are key customers of ALTCS; (2) performing a customer analysis of proxies; and (3) determining whether future surveys should be modified for proxies' input. Health care leaders can follow a similar approach for the non-ALTCS community.

How can AHCCCS Promote the Broader Choices of ALTCS Services?

It is clear from the survey that consumers are more satisfied with home and community-based care than with nursing facilities, although satisfaction in both settings is high. Consumers also want to participate more closely in directing their care.

Policy Issue:

- The state has the opportunity to (1) tell consumers and family members that "long term care" no longer means the only option is a nursing facility; (2) re-evaluate how money is allocated for long term care to encourage more home and community-based services; (3) give providers more information about choices and consumer needs; and (4) redefine which home and community-based settings and services can be offered to both the member and the caregiver.

Do Consumers Really Want to Choose their Health Plan?

For the first time, AHCCCS is offering ALTCS members a choice of managed care organizations to serve them, starting with Maricopa County in 2000 and the rest of the state in 2001. The project's survey of ALTCS members came about largely because of this opportunity to choose. Survey respondents underscored this change by emphasizing they wanted to choose who served them.

Policy Issue:

- These surveys are giving the state the chance to see why people choose a health care plan, and why this choice is important to them. A future survey and report will give better direction to establish the best benchmarks for improving care.

How can Consumers and Proxies Continue to Give their Valuable Input?

There is no question that input from ALTCS consumers is important to help identify which public policy issues should be tackled first.

Policy Issue:

- To continue receiving consumer input, state policy makers should (1) develop a survey center that can be used by long term care contractors, health plans and state agencies that deal with long term care and aging services; (2) share the cost of operating this center among long term care contractors, health plans and state agencies; (3) standardize the way surveys are worded and conducted so there is comparable feedback; and (4) develop a strategic plan to address issues gleaned from continuing input.

How Did the Maricopa County Long Term Care Plan Rate?

Overall, very well. Consumers were either satisfied or very satisfied with their doctors, case managers and caregivers in either home and community-based settings or nursing facilities. However, the ease with which doctors, caregivers or case managers could be reached received lower ratings.

Policy Issue:

- Show doctors, caregivers and case managers how they can be more available.
- Help doctors become more involved in the consumer's long term care services. Specifically, doctors should include the consumer or proxy in more decision-making, listen more, be more accessible, be more respectful and provide more help.

SUMMARY

This research project has helped identify what Baby Boomers know and don't know about long term care in Arizona. In short, they need much more education and information. This project also has helped assess the level of consumer satisfaction with ALTCS services – overall it is high and the system is working well, but there is much left to do.

Finally, this project has helped determine whether choice among consumers is an important consideration. It is, but we need a better understanding of why individuals want this choice.

All participants in this research clearly wanted a comprehensive approach to deal with an increasing demand on long term care services In Arizona. It has been the intent of this project's working group to help this come about by defining the issues and proposing viable options for policy makers.

ABOUT THE LTC SURVEY

To learn more about how to strategically plan for the future of our long term care systems in Arizona, the Flinn Foundation funded the first state Medicaid long term care consumer satisfaction survey.

ABOUT THE DATA

The quantitative data presented in this report was collected from participants of a consumer telephone survey. Individuals who participated were either direct members of the care (consumers) or making decisions for the consumer about their care (proxies).

The qualitative data presented in this report was collected from the participants of two Baby Boomer focus groups. The first group had experience with providing or seeking care for an elder relative within the LTC system in either a private pay or government program. The second focus group consisted of individuals who did not have experience with LTC.

ABOUT THE EXECUTIVE SUMMARY

This series, Final Report: Now and the Next Generation, is funded by a grant from The Flinn Foundation.

This report is the fifth in a series of six publications. Other documents available are:

1. What the Experts Say? (Literature Review)
2. What Current Consumers Say (Survey Book)
3. Survey Data Book
4. Baby Boomers: Who Me? (Focus Groups)
5. Trifold – Final Report Summary: Now and the Next Generation



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This report has been a joint effort of three organizations:
AHCCCS, HSAG, and Flinn Foundation.
The intent has been to define the issues and
propose viable options for policy-makers
regarding long term care in Arizona.

Additional copies can be obtained
from the AHCCCS website at
www.ahcccs.state.az.us.

Long Term Care:
Now and the Next Generation:
Final Report
Final Report Summary
Baby Boomers: Who Me?
What the Consumers Say
What the Experts Say
Survey Data Book